

# Genetic Discrimination and Privacy of Genetic Information:

## An Overview of State Legislation

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# The Background:

- The first state genetics nondiscrimination laws were passed in the 1970's
- Advancement of genetic technologies in the 1990's coincides with state legislative action to prevent genetics discrimination
- By 2001, 46 states have passed genetics legislation

# Legislation Varies Widely:

- Scope of coverage
- Protections afforded
  - Nondiscrimination
  - Privacy rights
- Enforcement schemes

# Definitions of Protected Information

- Narrow definitions, including “results of a genetic test” → TX, GA
- Broad definitions, extending to family histories, inherited characteristics,... → VA, NJ
- Exceptions and limitations are included in some broad definitions → CA, MI, FL

# What Information Is Protected?

	Personal test results	Family genetic history	Family character- istic	Inherited
HEALTH INSURANCE LEGISLATION	40	30	3	9
EMPLOYMENT LEGISLATION	28	11	11	14

# Protections and Penalties

- Protections afforded to genetic information
  - Access
  - Storage
  - Distribution
- Enforcement schemes
  - Civil, criminal, or no specific penalty provided

# Genetics Legislation: By Subject

- Nondiscrimination provisions
  - Health care insurance
  - Life, disability, or long-term care insurance
  - Employment discrimination
- Privacy provisions

# Health Insurance

- 46 states have some restrictions on the use of genetic information by health insurers
  - MS, PA, UT, and WA do not
- At least 42 restrict use of GI for eligibility
- 40 limit use of GI for classification or rating
- 26 states require informed consent for disclosure



# Health Insurance Discrimination

Prohibitions On Obtaining Genetic Info.	Prohibited Uses of Genetic Info.:  Eligibility	Risk Classification	Policy Rates	May Not Disclose Without Informed Consent:
25	42	40	8	26

# Life and Disability Insurance

- Regulated by 17 states
- Limits on the use of genetic information
  - Actuarial justification
  - Informed consent

# Employment Discrimination

- Scope of protected information varies
- Different employer acts are regulated
  - 28 states prohibit genetic discrimination in hiring, firing, and/or terms of employment
  - 22 restrict access to genetic information
  - 10 provide specific penalties for employment discrimination based on genetic information

# Employment: Prohibited Acts

Employer may not require genetic information	Employer may not request genetic information	Employer may not perform genetic tests	Employer may not obtain genetic information	Prohibitions on employer's use of genetic information
21	16	15	9	28

Adapted from Suter, 79 WAULQ 699

# Genetics Privacy

- Approximately 27 states provide privacy protections for genetic information
- 25 states require informed consent for disclosure of genetic information
- 2 states require informed consent to perform a genetic test, but do not regulate disclosure  
→ MI and SD
- 4 states create a property right

# Privacy Laws

Consent Required to Perform Genetic Tests	Consent Required to Obtain Genetic Information	Consent Required to Retain Genetic Information	Consent Required to Disclose Genetic Information	Specific Penalties for Privacy Violations
10	5	6	22	16

# Genetic Information As Property

- Colorado, Georgia, Florida, and Louisiana create “unique” or “exclusive” property interest in genetic information
- Oregon repealed its property-rights provision in 2001

# What's Next?

- Policy arguments behind genetics legislation
- “Genetic exceptionalism” is not universally accepted
- Changing technology